

RARE VIEWS

Tuberous Sclerosis Complex



Kari Luther Rosbeck
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Q. What inspired you to get involved with your organization?

A. I was hired by the TSC Alliance in 2001 by a mentor I had previously worked with at another organization. My role was the Director of Community Alliances - to lead the volunteer outreach program and establish volunteer branches across the country. My mentor believed I would be a great fit for the role because of my background in fundraising and community building and personally having lost a child to SIDS at just six weeks old. This personal experience gave me a deep understanding of how life can take unexpected turns and fueled my passion for helping other families avoid the grief I had endured.

As the organization grew, so did my responsibilities, and I eventually managed both outreach and fundraising efforts. I was later named Executive Vice President, working closely alongside the CEO. When the CEO left, I stepped in as the organization's interim leader and eventually into my role today as Chief Executive Officer.

Q. What is the biggest unmet need for your patients? For your caregivers?

A. One of the biggest unmet medical needs with tuberous sclerosis complex (TSC) is addressing refractory epilepsy and neuropsychiatric disorders. The TSC-Associated Neuropsychiatric Disorders (TAND) can impact everyone with TSC, including challenges related to sleep, anxiety, depression, and other mental health concerns.

On the service and family support side, a major focus is helping families navigate the transition from childhood to adulthood. This includes ensuring access to clinical care and support services for individuals with developmental disabilities. Many families struggle at this time, especially as services change, and even diminish in adulthood.

Additionally, caregiver burnout is a critical issue. It is essential to provide resources and support to ensure that caregivers receive the care and assistance they need while managing the challenges of supporting a loved one with TSC.

Q. Are there any new resources that you'd like patients and caregivers to know about?

A. In 2021, the TSC Navigator Program was developed as a simple and proactive online system to guide individuals through the journey of TSC in manageable steps. It allows users to take control of their learning experience, deciding how much information they want to absorb at a time. This program now serves as the centerpiece of the new website.

The updated website prominently features easy access to essential resources, i.e., finding a TSC clinic, consensus guideline, travel and lodging assistance, pharmacy resources, educational and community support, stories of hope, etc. And we have paired that with Support Navigators available to talk with individuals and families as they receive a diagnosis of TSC or when they are experiencing new challenges.

Additionally, a series of navigation guides are available, ensuring families have the support they need at every stage of their journey. These guides include:

1. Navigating the Early Years of TSC (in utero to 5 years of age)
2. Navigating the School Age Years of TSC (6 to 13 years of age)
3. Navigating the Transition Years of TSC (14 to 26 years of age)
4. Navigating the Adult Years of TSC

By offering these tailored resources, the TSC Navigator Program helps individuals and families confidently navigate the challenges of TSC with the information and support they need.

continued

Q.

How can the public help raise awareness and support your community?

A.

There are three key ways to make a meaningful impact in raising awareness and supporting the TSC community:

1. 50 Forward Fund

As part of our 50th anniversary celebration, the TSC Alliance has launched the 50 Forward Fund to advance our ambitious research business plan, with a goal of raising \$40 million.

2. Participate in Infantile Spasms Awareness Week

A major focus of awareness efforts is Infantile Spasms (IS) Awareness Week, as we strive to change the trajectory of the disease for all families affected by IS. IS Awareness Week occurs annually from December 1-7, and is spearheaded by the Infantile Spasms Action Network (ISAN), of which the TSC Alliance is a governing member. We invite community members to participate in IS Awareness Week.

3. Share Educational Resources

Access to accurate and timely information is crucial for those affected by TSC. Various organizations, including TSC Alliance, have made available educational videos, as an essential tool for newly diagnosed individuals and their families, helping them recognize symptoms, understand treatment options, and seek medical care as quickly as possible. The TSC Alliance educational videos and other patient and caregiver resources can be found on our website.

By supporting these initiatives, the public can help drive research, improve early diagnosis, and help families navigating TSC access the support they need.

Rare Views is an ongoing spotlight series brought to you by Mallinckrodt's Patient Engagement & Advocacy Team.